

Commission on Quality of Care and Advocacy for Persons with Disabilities

State Fiscal Year 2009-2010 Annual Report



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EXECUTIVE SUMMARY

The Commission on Quality of Care and Advocacy for Persons with Disabilities (the Commission) is charged with improving the quality of life for New Yorkers with disabilities and protecting their rights. The Commission provides independent oversight of the quality and cost-effectiveness of services provided by mental hygiene programs¹ in New York State and is also designated by the Governor to serve as the federally mandated “Protection and Advocacy” agency for New York State. This *State Fiscal Year 2009-10² Annual Report* describes the Commission’s activities in each of these critical mission areas.

During State Fiscal Year 2009-10, the Commission responded to over 41,000 requests for assistance, screened or reviewed over 12,000 allegations of abuse or deaths reported by mental hygiene programs, and conducted over 1,000 program reviews and independent investigations into those allegations and deaths. In addition, the Commission conducted 50 investigations related to the fiscal operations of licensed mental hygiene agencies.

Additional highlights include:

- Completed 489 residential child abuse investigations, a 35 percent increase from 2008³. The overall rate of indication for child abuse investigations was 14 percent.
- Conducted 345 individual reviews of agency investigations of allegations of adult abuse or neglect in the New York State mental hygiene system.
- Contracted with over 30 not-for-profit, community-based agencies providing information and referral services, training, direct representation in legal and administrative matters, and systemic advocacy, including class action litigation, which benefitted approximately 45,000 people.
- The Surrogate Decision-Making Committee program administered by the Commission assisted over 1,000 people with mental disabilities who were in need of non-emergency medical procedures.
- The Commission’s Technology-Related Assistance for Individuals with Disabilities (TRAID) program made over 11,000 loans of adaptive equipment and saved over \$1 million through recycling of assistive technology devices.
- Trained 5,586 individuals on issues of concern to people with disabilities, including the Americans with Disabilities Act, special education, and assistive technology.

¹ Includes all programs licensed or operated by the New York State Office of Mental Health, Office of People with Developmental Disabilities, and Office of Alcoholism and Substance Abuse.

² April 1, 2009 – March 31, 2010.

³ 2008 was based on the calendar year.

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OVERSIGHT

CHILDREN

Statewide Central Register (SCR) Investigations

During State Fiscal Year (SFY) 2009-10, the Commission received and investigated 489 allegations of child abuse or neglect reported to the Statewide Central Register (SCR) hotline involving children in Office of Mental Health (OMH), Office of People with Developmental Disabilities (OPWDD), and Office of Alcoholism and Substance Abuse Services (OASAS) operated or licensed residential facilities. This is a 35 percent increase in total investigations as compared to 2008⁴.

New York State Social Services and Mental Hygiene Laws, with few exceptions⁵, charge the Commission with investigating allegations of child abuse and neglect reported in residential mental hygiene facilities. Chapter 323 of the Laws of 2008 expanded the definition of residential facilities to include OASAS residential programs which serve youth under the age of 18. This law took effect in January, 2009.

Commission staff respond to all allegations reported to and accepted by the SCR within 24 hours to ensure the safety of the children involved. Investigations result in recommendations to the New York State Office of Children and Family Services (OCFS).

Recommendations from Commission investigations are that a reported allegation be “indicated,” meaning there is some credible evidence that abuse or neglect (as defined in Social Services Law) occurred, or that it be “unfounded,” meaning there is no credible evidence that abuse or neglect occurred. In unfounded cases, records are subsequently sealed.

The chart on the next page shows the number of allegations reported to the Commission from the SCR, and the number of those investigations that were indicated in OMH, OPWDD and OASAS licensed or operated facilities for SFY 2009-10.

⁴ Number of investigations in 2008 was based on the calendar year.

⁵ OCFS investigates all allegations of child abuse or neglect from the State Central Register at facilities with dual licensure from either OPWDD or OMH and OCFS. These facilities are often referred to as co-located facilities.

Reducing the Use of Punitive Practices in Residential Care

The Commission found that some OASAS licensed programs used the “Prospect Chair,” a behavioral intervention that restricts and isolates youth in care from the rest of the treatment setting.

In some instances, the “Prospect Chair” was found to be used for punitive purposes and adolescents were required to sit in the chair for long periods of time.

As a result of the Commission’s investigations and recommendations concerning the use of the “Prospect Chair,” several agencies ended this practice.

In addition, discussions were initiated with OASAS and OASAS began developing guidelines for providers requiring clear policies and procedures for the “Prospect Chair’s” use, limiting the time that the chair may be used and prohibiting the “Prospect Chair” from being used as punishment. These guidelines were issued in October, 2010.

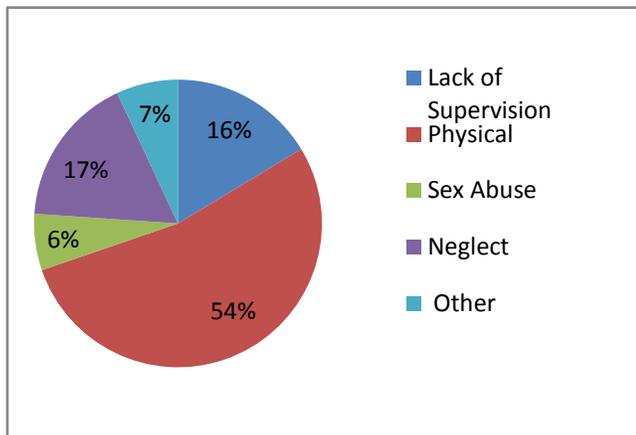
**Residential Child Abuse Investigations at OMH, OPWDD and OASAS
Licensed/Operated Residential Care Facilities SFY 2009-10 (n=489)**

<i>Auspice</i>	<i>Total Allegations</i>	<i>Recommended Indications⁶</i>
OMH – Licensed	141	20
OMH – State Operated	104	19
OPWDD – Licensed	187	26
OPWDD – State Operated	46	5
OASAS – Licensed ⁷	11	0
Totals	489	70

The overall rate of indication for residential child abuse investigations was 14 percent for SFY 2009-10. The indication rate in 2008 was also 14 percent.

The chart below identifies the types⁸ of residential child abuse allegations reported to the Commission by the SCR.

**Allegations of Residential Child Abuse Reported to
CQCAPD by State Central Register SFY 2009-10 (n=489)**



The category of “other” includes allegations that cover more than one type of abuse or issues such as improper medication, verbal abuse, or failure to provide adequate medical treatment.

⁶ Twenty-three investigations began in SFY 2009-10 but were not completed by the end of this time period.

⁷ Only four OASAS cases were closed in SFY 2009-10.

⁸ Physical abuse includes allegations regarding the use of restraints.

Improving Care

An adult services community agency started a residential program for children with developmental disabilities who either were living in out-of-state residential facilities or would have been referred to out-of-state facilities. Many of these children exhibited disruptive behavior.

This program had not developed policies and procedures that were appropriate for children, nor did the policies and staff training address the significant behavioral challenges that many of these children presented.

The Commission received several child abuse reports through the SCR from this program. Recommendations generated by the Commission’s investigations resulted in improvements in staff training and the development of child-appropriate policies for supervision, crisis care, outings, incident reporting and family involvement and contact.

In addition, the Commission facilitated contact with OPWDD to provide further assistance to the program.

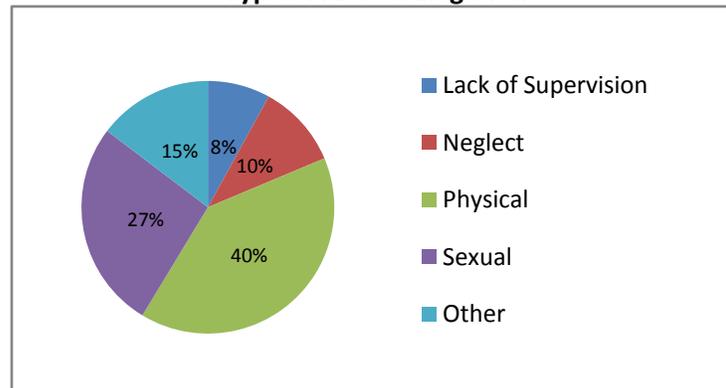
As a result of these efforts, there have been fewer allegations of abuse and neglect reported to the SCR from this program.

Non-SCR Reviews

Mental hygiene programs are required to report allegations of abuse and mistreatment to the Commission. Some of these allegations of abuse and neglect are not accepted by the SCR, or the facts place them outside of the jurisdiction of Social Services Law. The reporting agency must investigate each allegation⁹. In addition, OMH, OPWDD and OASAS central offices may conduct investigations into allegations.

Each allegation reported to the Commission is screened and a determination is made on how to handle the matter. Depending upon the nature of the allegation, the Commission may review the quality of the agency investigation, and may seek corrective actions or re-investigation by the agency, or choose to open an independent care and treatment review. The chart below identifies the types of non-SCR allegations reviewed by the Commission.

**Reviews of Children’s Non-SCR Allegations from OMH & OPWDD
Operated or Licensed Programs SFY 2009-10 (n=75)
Type of Abuse Allegation**



The types of abuse alleged in children’s non-SCR reviews were similar to those received by the Commission through the SCR. Physical abuse was the most frequent allegation reviewed by the Commission.

Children’s Care and Treatment Reviews

Care and Treatment Reviews may be initiated in response to complaints regarding the care and treatment of children with disabilities in mental hygiene facilities, or when the Commission has additional programmatic concerns after the completion of one or more SCR investigations at a facility. Care and Treatment Reviews address a variety of issues that affect the rights, safety, and care of a particular child, which may include, but are not limited to, medication management, access to food and clothing, agency environmental concerns, inappropriate discharge and inadequate medical care.

⁹ These investigations must be performed in accordance with the requirements of Part 524 (OMH) or Part 624 (OPWDD) of Volume 14 of the New York Code of Rules and Regulations.

The chart below lists reviews undertaken by the Commission regarding the care and treatment of children residing in OMH or OPWDD-licensed or operated residential care facilities.¹⁰

**Children’s Care and Treatment Reviews for OMH and OPWDD
Facilities SFY 2009-10 (n=31)**

Auspice	Total Care and Treatment Reviews
OMH – Licensed	5
OMH – State Operated	2
OPWDD – Licensed	23
OPWDD – State Operated	1
Total	31

¹⁰ OASAS is in the process of developing incident reporting regulations. The Commission did not conduct any care and treatment reviews in OASAS programs in SFY 2009-10.

ADULTS

The Commission conducted 230 individual reviews of agency investigations of allegations of adult abuse or neglect and 115 care and treatment reviews in the New York State mental hygiene system during SFY 2009-10. All programs operated or licensed by the Office of Mental Health (OMH) and the Office for People with Developmental Disabilities (OPWDD) are required to report all allegations of abuse or neglect to the Commission.¹¹

Adult Abuse Reviews

The Commission provides independent oversight of serious incidents and investigations in the mental hygiene system. The reporting agency must investigate each allegation¹² and OMH, OPWDD, and OASAS may also conduct investigations into allegations. The Commission screens each allegation and, depending upon the nature of the allegation, the Commission may review the quality of the agency investigation and, if necessary, seek corrective actions or re-investigation by the agency.

In SFY 2009-10, the Commission screened 9,795 allegations of adult abuse or neglect of individuals receiving services from OMH and OPWDD operated or licensed programs and conducted independent reviews of 230 individual allegations of adult abuse or neglect. The majority of allegations reviewed involve people living in residential programs.

A breakdown by agency auspice is presented in the following chart.

**Adult Abuse & Neglect Allegations from OMH and OPWDD Programs
Screened for Further Action: SFY-2009-10 (n=9,795)**

Auspice	Allegations Screened	CQCAPD Reviews
OPWDD - Licensed	6,891	112
OPWDD - State Operated	2,273	71
OMH - Licensed	309	23
OMH - State Operated	322	24
Totals	9,795	230

¹¹ OASAS is in the process of developing incident reporting regulations. The Commission did not conduct any Adult reviews in OASAS facilities in SFY 2009-10.

¹² These investigations must be conducted in accordance with the requirements of Part 524 (OMH) or Part 624 (OPWDD) of Volume 14 of the New York Code of Rules and Regulations.

Supporting Patient Rights, Facilitating System Change

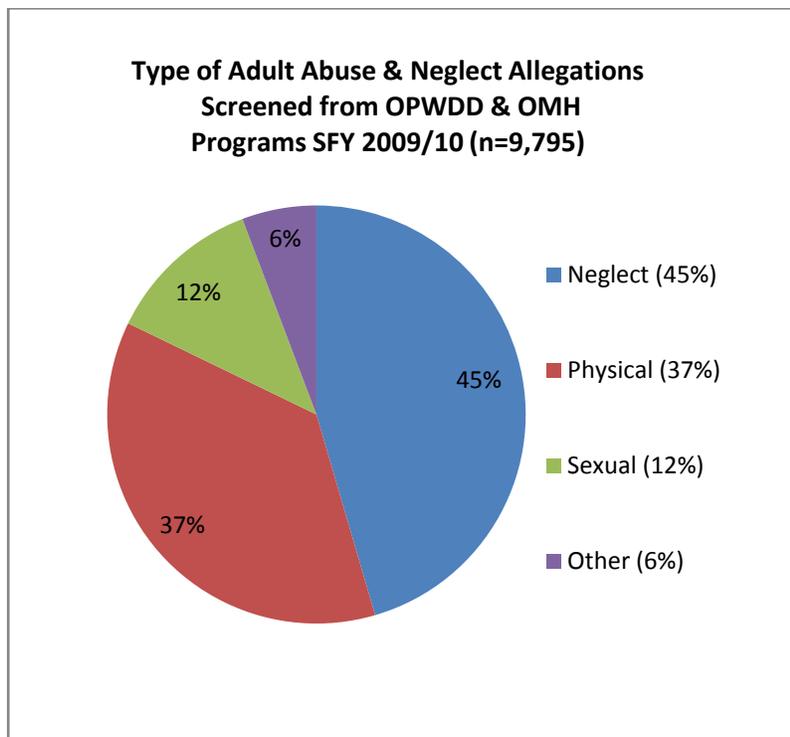
Commission reviews revealed that psychiatrists at a number of hospitals were issuing standing physician orders written for PRN (as needed) intramuscular (IM) psychotropic medications. The rationale for PRN IM administration was often “agitation” or “severe agitation.”

Some hospitals administered the PRN IMs over the objection of the patient which is in violation of OMH regulations. Psychotropic medication may only be given over objection in an emergency situation when necessary to prevent imminent harm to self or others or pursuant to a court order.

The Commission addressed these concerns with the individual hospitals. In addition, the Commission and its Mental Hygiene Medical Review Board asked OMH to address the issue.

In April, 2010, OMH issued a guidance document on the use of PRN psychotropic medications. This document, issued to all providers and available on the OMH website, states that patients have the right to refuse treatment and that PRNs for agitation should only be used on a voluntary basis.

As the chart below shows, neglect, physical abuse and sexual abuse were the most frequent types of adult abuse allegations.



Promoting Resident Rights

The Commission reviewed a facility investigation into alleged sexual abuse of five people with developmental disabilities by a staff member at a community residence and found that people living in the home were reluctant to report the alleged abuse, in part because they did not know how to report incidents of abuse.

In response to the Commission's recommendations, the agency revised its resident rights training to ensure that all residents were informed about their right to be free from abuse, understood what different types of abuse were, and how to report abuse.

Adult Care and Treatment Reviews

Care and Treatment Reviews are often begun in response to individual requests or complaints, or are initiated by Commission investigators who have identified concerns regarding a particular individual in the course of another investigation or review. Care and Treatment Reviews address a variety of issues that affect the rights, safety or care of a particular individual. Issues addressed in the Commission's Care and Treatment Reviews include, but are not limited to, complaints or allegations involving medication management, access to food and clothing, treatment planning, environmental concerns, discharge planning and the adequacy of medical care.

The chart on the next page lists reviews undertaken regarding the care and treatment of individuals receiving services from OMH or OPWDD operated or licensed programs¹³. Six

¹³ OASAS is in the process of developing incident reporting regulations. The Commission did not conduct any Adult Care and Treatment reviews in OASAS facilities in SFY 2009-10.

reviews were conducted as facility wide reviews that involve multiple investigators at multiple units in a large facility or multiple program sites for one agency.

Adult Care and Treatment Reviews for OMH and OPWDD Programs SFY 2009/10 (n=115)

Auspice	Adult Care and Treatment Reviews
OPWDD - Licensed	44
OPWDD - State Operated	15
OMH - Licensed	28
OMH - State Operated	28
Totals	115

Improving Hiring and Investigation Practices

The Commission received an anonymous call about extensive drug use and drug dealing by staff members working in a community-based residential program for adults with developmental disabilities.

As a result of the Commission’s review and recommendations, the staff found to be using drugs were terminated and the agency undertook a number of steps to address factors leading up to this incident, including:

- Developing and implementing a drug testing policy for staff;
- Initiating unannounced visits to community residences;
- Contracting with an outside agency to review and revise its entire human services department and its procedures; and
- Obtaining incident management training for all staff.

ADULT HOMES

The Commission oversees the quality of care provided to people living in impacted¹⁴ adult homes by conducting comprehensive reviews of adult homes, investigating complaints and deaths of adult home residents, and monitoring adult home closures.

In SFY 2009-10, the Commission conducted 18 comprehensive reviews of adult homes serving approximately 1,500 people. During these reviews, staff assessed basic living conditions, fire safety, food services, personal care, medication management, case management, resident activities and resident rights. Reports of findings and, where warranted, requests for plans of corrective action, were issued to all adult homes reviewed, with copies to the Department of Health, Office of Mental Health and Office for the Aging.

The Commission made 12 visits to homes to investigate deaths or complaints. The Commission also monitored the closure of one adult home serving people who received mental health services to ensure that the people moving out of the home were provided a choice in the selection of a new place to live, and that appropriate services and supports were in place when they moved.

In addition, the Commission administers funding for the Adult Home Advocacy Project. This program provides legal and lay advocacy services to people living in adult homes in New York City and Long Island. During SFY 2009-10, one of the legal services agencies that receives project funds successfully prevented, for the third year in a row, an adult home from raising the rent for residents who receive Supplemental Social Security Income (SSI).

Improving Care for People with Diabetes

An adult home administrator reported to the Commission that people with diabetes living in the home often took their medication for diabetes but did not eat their meal.

This information was not reported to the home-health nurses who treated people with diabetes in the home or to their doctors. One person living in the home was hospitalized for an episode of extreme hypoglycemia as a result of not eating meals.

In response to the Commission's recommendations, the home instituted a new procedure to ensure appropriate communication between adult home staff and home health nurses and/or physicians regarding meal consumption and medication compliance for people with diabetes.

¹⁴ Adult homes serving significant numbers of individuals with mental disabilities (25 residents or 25 percent, whichever is less) are considered "impacted."

Prison Mental Health Care

Chapter 1 of the Laws of 2008, the Special Housing Unit (SHU) Exclusion Law, gave the Commission the responsibility to monitor the quality of mental health care provided to people who are incarcerated in correctional facilities operated by the New York State Department of Correctional Services (DOCS). In order to carry out this responsibility, the Commission conducts mental health service reviews of unusual or suspicious deaths of people who are incarcerated. The Commission also conducts systemic reviews of mental health services provided in State correctional facilities.

During SFY 2009-10, the Commission initiated 12 mental health service reviews. The purpose of these reviews was to ascertain the quality of mental health care provided to the inmate prior to his or her death.

The Commission completed a review of Residential Crisis Treatment Programs (RCTPs), its first systemic review of mental health programs in correctional facilities. This review was finalized in July 2010 and is available on the Commission's website www.cqc.ny.gov.

In January 2010, the Commission began working with DOCS and the Office of Mental Health (OMH) to develop the training curriculum for DOCS staff working in residential mental health treatment units. This additional training is one of the requirements of the SHU Exclusion Law and will start in July 2011.

In addition, the Commission continued to meet with former inmates, family members of people who are incarcerated and other advocacy organizations to solicit recommendations for improving the quality of mental health care.

In July 2011, the Commission's responsibilities will expand to include:

- Oversight of assessment, treatment, discipline and restrictions in all residential mental health treatment units operating in New York State correctional facilities;
- Authority to recommend an assessment to see if an inmate should be transferred from SHU to a residential mental health treatment unit;
- Reporting on implementation of the SHU Exclusion Law annually; and
- Appointing an advisory committee on psychiatric correctional care.

Improving Mental Health Care

The RCTP review resulted in recommendations to improve the care provided to inmates in need of immediate mental health evaluation and or observation and treatment. DOCS and OMH agreed to:

Increase monitoring to ensure all inmates with a serious mental illness are appropriately identified;

Provide additional training to mental health staff; and

Monitor the temperature in observation cells to ensure that it is appropriate.

DEATH REVIEWS

In SFY 2009-10, the Commission investigated or reviewed 198 individual deaths. Sixty-two percent of all deaths reported to the Commission were categorized as natural causes and six percent of all deaths were by suicide¹⁵. The Commission reviewed or investigated 27 percent of the deaths by suicide. The chart below shows the number of deaths reported to the Commission and the number investigated or reviewed.

Deaths Reported to the Commission from Mental Hygiene Programs (SFY - 2009/10)

Action	Number
Total Reported	2,416
CQCAPD Investigations	102
CQCAPD Reviews	96

State-operated or licensed Office of Mental Health (OMH), Office of People with Developmental Disabilities (OPWDD), and Office of Alcoholism and Substance Abuse Services (OASAS) programs are required to report deaths of all individuals receiving services to the Commission. Adult homes and residences for adults licensed by the Department of Health (DOH) are also required to report the deaths of individuals receiving mental hygiene services to the Commission. The chart below lists the number of deaths reported to the commission by auspice.

Deaths Reported to the Commission by Auspice (SFY - 2009-2010)

Auspice	Deaths Reported to the Commission
DOH/Adult Home	174
OMH	1,083
OPWDD	796
OASAS	363
Total	2,416

Commission staff nurses screen all death reports to determine whether or not further review or investigation by the Commission is

¹⁵ The majority of suicide deaths reported to the Commission were people who were receiving services from the Office of Mental Health (OMH).

Reducing Over-Medication

A woman in her early forties was admitted to a hospital psychiatric unit. Initially she was calm but became increasingly agitated and hospital staff had a difficult time caring for her.

Staff at the hospital had no clear strategy for managing her behavior and, instead, administered multiple doses of a variety of different medications and placed her in isolation.

While in isolation she was monitored every 15 minutes and was reported to sleep during the night. During a monitoring visit she was found unresponsive. Staff initiated CPR and administered emergency treatment, but she could not be resuscitated.

The Commission, in consultation with the Mental Hygiene Medical Review Board, found that the woman had been over-medicated.

After considering the Commission's findings and recommendations, the hospital developed new policies addressing the management of severely agitated patients and provided staff training on alternatives to medicating patients who are agitated.

warranted. In such cases the Commission will either review the facility investigation or conduct an on-site investigation of its own.

The Commission may conduct an on-site investigation when:

- an individual commits suicide, either while in a hospital or licensed residential facility, or within one week of discharge from the facility, or within 72 hours of presentation at a hospital emergency room;
- there is an allegation of abuse involving the circumstances of death;
- a death occurs within several days of restraint or seclusion, or after an altercation with staff or peers;
- questions are raised regarding the quality of medical care prior to the death; and
- an agency or individual contacts the Commission with concerns.

Mental Hygiene Medical Review Board

The Mental Hygiene Medical Review Board (MRB) consists of up to 15 volunteer physicians appointed by the Governor. These physicians are specialists in a variety of areas, including forensic pathology, psychiatry, surgery and internal medicine and provide expert advice to the Commission when medical issues arise in the course of death investigations, and reviews of allegations of abuse and neglect.

In 2009, 43 cases were referred to the MRB for consultation or review. In addition, the MRB met with commissioners and/or senior staff from the New York State Offices of Mental Health, Persons with Developmental Disabilities, and Alcoholism and Substance Abuse Services, and discussed: the use of standing PRN (as needed) intramuscular (IM) psychotropic medication orders, assessing the risk of physical and emotional harm in child abuse investigations, co-occurring disorders, health-related issues for people with developmental disabilities, and standards of medical care for people with chronic mental illness.

FISCAL REVIEWS AND INVESTIGATIONS

The Commission is charged under New York State law to review the cost-effectiveness of the management, supervision, and delivery of any program that is operated, or licensed, or funded by the Office of Persons with Developmental Disabilities, Office of Mental Health or Office of Alcoholism and Substance Abuse. The Commission also oversees the financial operations of adult homes licensed by the Department of Health in which either 25 percent or 25 (whichever is less) of the people living in adult homes have a mental illness.

During SFY 2009-10, the Commission worked on more than 50 cases, ranging from reviews of personal allowance complaints to complex corporate investigations of fraud, waste, and abuse. Whenever Medicaid reimbursement is involved, the Commission's fiscal investigation determines whether the funds were spent for their intended purpose and are in compliance

with state and federal regulations. If it appears that Medicaid funds may have been obtained inappropriately or misapplied, referrals are made to the Office of Medicaid Inspector General and other appropriate law enforcement agencies.

Highlights from the Commission's fiscal investigations in SFY 2009-10 included the restitution of over \$1 million in Medicaid funds, the restoration of over \$4,500 in personal allowance funds owed to a person receiving services, and the closure of one agency due to financial malfeasance. The full report on the agency closure can be found on the Commission's website: www.cqc.ny.gov.

ADVOCACY

PROTECTION AND ADVOCACY

The Commission is designated to administer all eight of the federal Protection & Advocacy (P&A) programs in New York State. The first P&A program was created by Congress in 1975. In addition, New York State provides funding for advocacy programs for people living in adult homes and parents with psychiatric disabilities. The Commission is designated to administer these programs as well.

In Federal Fiscal Year (FFY) 2008-09, the Commission contracted with over 30 not-for-profit agencies to provide P&A programs throughout the State. These programs served approximately 45,000 people by providing information and referral services, training, direct representation in legal and administrative matters, and systemic advocacy, including class action litigation.

The P&A programs that are administered by the Commission are:

Federal P&A Programs¹⁶

- 1. *Protection and Advocacy for Persons with Developmental Disabilities (PADD)*** assists people with developmental disabilities and their families. Over 50 percent of PADD cases involve children under the age of 21 and typically concern access to appropriate special education and related services.
Number of Individuals Impacted 11,639
- 2. *Protection and Advocacy for Individuals with Mental Illness (PAIMI)*** assists people with mental illness with advocacy-related services.
Number of Individuals Impacted 9,592
- 3. *Client Assistance Program (CAP)*** assists people with disabilities secure training and services that support employment and independent living.
Number of Individuals Impacted 6,684
- 4. *Protection and Advocacy for Individual Rights (PAIR)*** helps people with disabilities not covered by the federally authorized PADD, PAIMI or CAP programs.
Number of Individuals Impacted 3,661

Improving Educational Opportunities

A young child was placed by his school's Committee on Special Education (CSE) in a school program that allegedly did not address his needs. While he was in this program he was physically restrained daily, and the school district used a furnished, un-occupied office as a time-out room.

The P&A program assisted the family in obtaining a more appropriate educational placement for the child.

The P&A program also helped the school eliminate the use of dangerous physical restraints and increase training for school staff on alternatives to the use of restraints.

¹⁶ Based on the Federal Fiscal Year 2008-09 (10/ 1/ 2008 – 9/30/2009).

5. ***Protection and Advocacy for Assistive Technology (PAAT)*** aids people with disabilities who require assistive devices (e.g. wheelchairs, special communication equipment).
Number of Individuals Impacted 224
6. ***Protection and Advocacy for Beneficiaries of Social Security (PABBS)*** assist people receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) obtain, maintain or regain employment.
Number of Individuals Impacted 3,401
7. ***Protection and Advocacy for Persons with Traumatic Brain Injury (PATBI)*** provides legal and other advocacy services for people with traumatic brain injury.
Number of Individuals Impacted 838
8. ***Protection and Advocacy for Voting Access (PAVA)*** ensures the full participation of people with disabilities in the electoral process.
Number of Individuals Impacted 5,870

State P&A Programs

1. ***Parents with Psychiatric Disabilities Legal Advocacy (PPDLA) Project***¹⁷ provides legal and other advocacy services to parents with psychiatric disabilities experiencing issues around parenting.
Number of Individuals Impacted 1,862¹⁸
2. ***Adult Home Advocacy*** provides advocacy services for people with mental illness living in adult homes.
Number of Individuals Impacted 1,328

For more information on the Commission’s Protection and Advocacy programs, visit www.cqc.state.ny.gov.

Reuniting Families

A woman diagnosed with co-occurring bi-polar and substance abuse disorders had her two children removed from her care after a petition of neglect was filed. After the petition was filed, the woman immediately began receiving drug treatment and mental health services.

After completing one year of treatment services, the Parents with Psychiatric Disabilities project attorney helped her obtain visitation. The attorney also assisted her in identifying and enrolling in a therapeutic parenting class.

During this time she had another baby who remained in her care. In time, all of her children were returned to her care.

¹⁷ Authorized by Chapter 54 of the NYS Laws of 2007. Funding for this program ended April 30, 2010.

¹⁸ May 1, 2009 – April 30, 2010.

SURROGATE DECISION-MAKING COMMITTEE

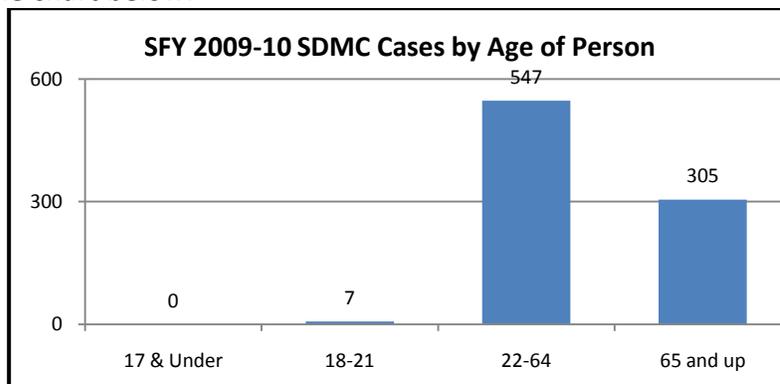
Surrogate Decision-Making Committee (SDMC) panels were established as an alternative approach to the court system for obtaining informed consent for non-emergency medical treatment for persons with mental disabilities who:

- reside or once resided in facilities or programs licensed, operated, or funded by the New York State Offices of Mental Health (OMH) and of People with Developmental Disabilities (OPWDD), or who receive or once received case management or service coordination approved, funded or provided by OPWDD;
- lack the mental capacity to provide informed consent; and
- do not have a family member or other legally authorized surrogate to act on their behalf.

SDMC uses specially trained volunteer panels to review declarations regarding a person's capacity and need for treatment and then renders decisions at a hearing. Whenever possible, the person in need of the treatment attends the hearing. On average, SDMC decisions are made within 16 days from the time the case is sent to the Commission. This service is offered free of charge.

In SFY 2009-10, 1,670 volunteers assisted 1,073 people in need of medical procedures and 859 people had their case sent to a Surrogate Decision-Making Committee (SDMC) for a decision. The most requested medical procedures were: digestive (40 percent), dental (15 percent), genitourinary (11 percent), and diagnostic (10 percent).

Ninety-five percent of the people whose cases were considered by a SDMC had a developmental disability and 5 percent had a psychiatric disability; 60 percent were male and 40 percent were female. The age of people whose cases were considered by a SDMC is broken out in the chart below.



SDMC Provides Timely Access to Care

A 63 year old man living in a nursing home received services from the SDMC program twice in two months in 2009.

In the first instance, the SDMC panel approved an MRI and full-body CT scan for diagnostic purposes.

The CT scan revealed cancer and, when the man's condition deteriorated rapidly, it was recommended that he receive hospice services and palliative treatments to make him more comfortable.

The SDMC committee granted consent for this request within a week of receiving the request and the man was able to receive quality end-of-life care.

To find out more information about the SDMC Program or to become a volunteer, please visit www.cqc.ny.gov.

ASSISTIVE TECHNOLOGY

Through a federal grant from the Rehabilitation Services Administration (RSA), the Commission administers the Technology-Related Assistance for Individuals with Disabilities (TRAID) Program. TRAID's mission is to coordinate statewide activities to increase access to and acquisition of assistive technology in education, employment, community living, and information technology and telecommunications.

TRAID contracts with 12 regional centers to provide information, training, device demonstration and loan, technical assistance and advocacy on how to obtain and use assistive technology services and devices. During 2009¹⁹, 2,468 devices were re-utilized or recycled for a savings of \$1,016,110 to individuals and programs. Additionally, 7,596 equipment loans were made and 4,525 devices were demonstrated to persons with disabilities.

The TRAID Program, in collaboration with the NYS Department of Health Early Intervention Program, provides funding to the regional centers for equipment loan libraries for infants and toddlers with disabilities and their families. During 2009²⁰, the regional centers re-utilized or recycled 163 devices used by children and their families receiving Early Intervention services for a cost savings of \$70,772. There were 3,904 loans of devices made and 881 devices demonstrated.

More information on TRAID and the location of Regional TRAID Centers (RTC) can be found on the Commission's website: <http://cqc.ny.gov/advocacy/assistive-technology>.

Helping People Communicate

TRAID received a call from a speech-language pathologist at a hospital who was working with a woman who lost the ability to speak due to oral cancer.

The speech pathologist wanted the woman to get started with some form of communication device so that she would be ready for procurement of a permanent device upon discharge.

The TRAID program brought five devices for the woman to try out while she was in the hospital. The woman selected the device she liked best and, for the first time in months, was able to communicate with her children and husband and even ask questions of her doctors.

The woman's speech pathologist was able to justify procurement of the device through Medicaid based on the trial experience.

¹⁹ Numbers are based on the federal fiscal year 2008-09 (October 1, 2008-September 30, 2009).

²⁰ Numbers are based on the federal fiscal year 2008-09 (October 1, 2008-September 30, 2009).

TRAINING AND TECHNICAL ASSISTANCE

In SFY 2009-2010, the Commission responded to over 41,000 requests for assistance. The majority of these requests, 37,000, were received through the Commission's toll-free telephone hotline. This hotline is used by people who have concerns about their care or someone else's care and by people who have questions or need assistance obtaining services. In addition, the Commission and its contract agencies responded to 4,065 technical assistance calls on a variety of disability-related topics, including topics of concern to people with physical and/or sensory disabilities.

The Commission and its contract agencies provided 199 trainings to 5,586 individuals across New York State during SFY 2009-10. Training was provided on a range of topics including the Americans with Disabilities Act, Help America Vote Act (HAVA), accessibility, special education, assistive technology, and disability and diversity awareness. Trainings were conducted in various school, community and workplace settings.

The Commission also conducted two trainings on incident management and investigations. Staff from State-operated and licensed mental hygiene agencies from across the State attended the trainings as did staff from State agencies, including the Office of Alcoholism and Substance Abuse Services, and the Education Department.

Additional activities:

- Partnered with the New York State Office of Mental Health and two statewide family-run organizations to begin developing training, with parents as co-trainers, on special education service planning to improve awareness of special education resources for children who have been classified as having an emotional disturbance under the Individuals with Disabilities Education Act (IDEA). This training is part of the New York State Children's Plan, and will be provided to families, youth, schools and service providers.
- Supplemented information provided by the New York State Board of Elections on issues important to people with disabilities by providing information about HAVA and other voter information on the Commission's website and by providing technical assistance for making polling sites accessible.

Addressing People's Concerns

The following are examples of ways the Commission assisted people who called its toll-free telephone hotline:

A woman who uses a wheel chair was an inpatient at a psychiatric hospital. She was concerned about her safety because there was a male patient with a history of assaulting female patients on the same unit. She conveyed her concerns about her safety due to her limited mobility to her doctor, the director, and the patient advocate at the hospital. After a few days passed and nothing was done, she called the Commission's hotline. After the Commission contacted the hospital, she was moved to a different unit.

In addition, the Commission assists callers who want information about a diverse array of community services and supports, including employment supports, and opportunities, housing, health insurance, and educational supports and services.

INTERAGENCY COORDINATING COUNCIL FOR SERVICES TO PERSONS WHO ARE DEAF, DEAF-BLIND OR HARD OF HEARING

Chapter 174 of the Laws of 2007 created the Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-blind or Hard of Hearing (the Council) to promote a comprehensive service system for people who are deaf, deaf-blind or hard of hearing. The Council is comprised of 15 members; 8 members are appointed by the Governor and the Legislature and 7 members represent state agencies²¹. The Commission chairs the Council.

The initial Council report, describing the progress that has been made in addressing the requirements of Chapter 174, was issued in November 2009. This report identifies the 2009 priorities of the Council, which include: maintaining data on the prevalence of deafness, deaf-blindness and other hearing loss, serving as a clearinghouse on services and resources, and receiving and referring complaints to the appropriate regulatory agency.

One of the changes brought about by the Council was expanding the Commission's existing infrastructure, which handles requests for services and resources through a toll-free voice, text and relay accessible telephone line and website, to provide national, statewide, and regional services and resources for persons with all types of disabilities including individuals who are deaf, deaf-blind or hard of hearing. This referral and resource infrastructure will be expanded through increased utilization of the Regional 2-1-1 Health and Human Services Related Information and Referral Networks. The Commission will be collaborating with the Statewide 2-1-1 Collaborative by providing updated resources and services for persons who are deaf, deaf-blind or hard of hearing and helping to ensure their regional services are accessible.

²¹ The agencies are: Office of Children and Family Services, Office for Aging, Department of Health, Department of Labor, Education Department and the Public Service Commission and the Commission.

Reducing Isolation

Some local TV stations do not close-caption broadcasts and this contributes to isolation for people who have a hearing disability.

The Commission received a call from a mother of a child who is deaf. The mother had written to the TV station requesting captioning and the station did not respond.

The Commission provided her with the FCC requirements regarding captioning. The mother filed a complaint with the FCC and the TV station agreed to start captioning.

The mother reported to the Commission that a "sweet smile broke her daughter's lips" when she was able to watch TV and understand the topic.

For more information on the Interagency Coordinating Council for Services to Persons who are Deaf, Deaf-blind or Hard of Hearing, visit www.cqc.ny.gov/advocacy/int-eragency-coordinating-council.

MEDIA & PUBLICATIONS

- July 2009: *“Europa Associates For Community Services, Inc.: A Study into the Failure of a Board to Exercise its Fiduciary Responsibilities.”* This report chronicles the failure of the board of directors to meet its fiduciary duty of overseeing a small community-based agency providing services to persons with developmental disabilities. Based on the Commission’s review, the Office of People with Developmental Disabilities²² closed the agency and ensured that the people being served by the agency were transferred to other providers.
- July 2009: *“Hospital Discharge Survey.”* The Commission invited hospitals providing psychiatric inpatient care to participate in a survey. This survey was prompted by concerns expressed to the Commission by parents, providers and its own investigators about difficulties sometimes encountered in obtaining timely and appropriate discharge for people who are hospitalized in psychiatric units – particularly people who have a mental illness and a developmental disability.
- March 2010: *“The Quality Initiative: What People with Disabilities and Their Families Said About Quality of Life.”* This report summarizes what people with disabilities and their family members said about a wide variety of life areas, including employment, education, transportation, housing, health, community participation and more. The information in this report provides a framework for policy makers, government agencies, advocacy organizations, providers, individuals and family members to use when planning, providing, funding or regulating services for people with disabilities.
- March 2010: *“Veterans with Disabilities, A New Kind of Engagement.”* This video highlights the realities of veterans with disabilities and the many critical issues which they face in returning to their civilian lives. The show features the stories of two returning veterans, one a Vietnam Era veteran and the second a veteran of the conflict in Iraq. Experienced national and local advocates for veterans with disabilities provide their insights into veteran issues and strategies to address them.
- *“This May Happen in Your Community”* educates the public about physical accessibility and disability rights issues. The series of stories is based on technical assistance inquiries or complaints that the Commission receives.
- *“Could This Happen in Your Program?”* is a series of stories based on Commission investigations. The objective of the series is to prevent accidents and other problems in programs by learning from the experience of others.

The Commission’s media and publications can be found on the Commission’s website: www.cqc.ny.gov.

²² This agency was the Office of Mental Retardation and Developmental Disabilities at the time this report was published.